
Practice Guidelines for

Managing Critical Health Care Decisions

Including

Advance Health Care Directives



Ministry for Children and Families
Child Protection Division

November 1999

Table of Contents

Introduction	3
Terms used in these practice guidelines	4
1. Your role in managing critical health care decisions	6
Who may consent to or refuse a proposed health care decision	9
2. Determining a child's capability	10
3. Planning an advance health care directive	11
Do Not Resuscitate Orders	12
4. Resolving disagreements over a health care decision	14
5. Referring disputed health care matters to an ethics committee	15
Appendix 1: Section 29 - CFCSA	18
Appendix 2: Guardianship Practice Standard #32	19
Appendix 3: Sample Advance Health Care Directive form	20
Appendix 4: A child's right to determine health care	23
Appendix 5: Determining the capability of a child: Guidelines for physicians	25

Acknowledgments

The development of these practice guidelines is the result of more than a year of hard work on the part of a number of individuals from both community and government.

Thanks go to the dedicated members of the working group who contributed their valuable experience, knowledge and energy to these practice guidelines:

Dr. Shaun Peck	Deputy Provincial Health Officer, Ministry of Health
Lenora Angel	Regional Executive Director, MCF
Jamie Sork	Social Work, Canuck Place
Karen Breau	Social Work, BC Children's Hospital
Michael Davies	Legal Services Branch, Ministry of Attorney General
Rick Preston	Community Living Services (Special Needs), MCF
Bruce Leslie	Aboriginal Relations Branch, MCF
Gaylene Wilkinson	Policy Division, MCF
Ray Bronson	Child Protection Division, MCF

A special thanks to BC Children's Hospital's Ethics Committee for their support and input.

Introduction

This document sets out the ministry's practice guidelines for managing critical health care decisions, including advance directives, for medically fragile children and youth.

Unlike practice standards, practice guidelines are not compulsory. They provide recommended procedures to help social workers meet the expectations in policy, child protection standards, and guardianship standards that apply in specific child protection and guardianship situations.

When to use these practice guidelines

These guidelines apply where a critical health care decision must be made about a child who has significant health care needs that are immediately life threatening or terminal, including:

- a child in a family that is receiving support services from the ministry
- a child in care
- a child who comes to the ministry's attention through a child protection report concerning the child's critical health care needs

Sample situations in which a critical health care decision may be required:

The guidelines in this document apply to situations such as the following:

- where a child is in continuing care and health care providers ask for a decision on whether to provide intensive life support treatment to maintain the child's life or whether to continue to offer the child palliative care.
- where a child protection report indicates that a child or the child's parent is refusing to consent to health care that is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's health.
- where a medically fragile child is receiving voluntary family service or protective family service and there is concern about whether the health care the child is receiving is effective or beneficial.

Meeting child protection and guardianship standards

In all cases where you are managing a critical health care decision about a child, you must ensure that all relevant practice standards are met.

- In the case of a Protective Family Service case, including protection intakes and investigations, all of the Practice Standards for Child Protection apply.
- In the case of a child in care, Practice Standard for Guardianship #32 specifically applies (see Appendix 2).

Guiding principles

These practice guidelines are to be interpreted and administered so that the safety and well-being of children are the paramount considerations and in accordance with the guiding principles and service delivery principles of the *Child, Family and Community Service Act*.

Practice principles for making critical health care decisions

If a situation is not covered by the practice guidelines in this document, the following practice principles should guide your actions:

- Subject to s. 29 of the *Child, Family and Community Service Act*, a child who is assessed as capable has the right to consent to or refuse health care as long as the decision is made voluntarily and the health care provider:
 - has fully explained the risks and the benefits of health care, and
 - is satisfied the child understands the nature and consequences of the health care

Note: A capable child's right to consent to health care is qualified by s. 29 of the *Child, Family and Community Service Act* (see Appendix 1). You may consider an application for a court order authorizing health care under s. 29 if, in the opinion of two medical practitioners, the health care is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's life.

- End-of-life decisions made by the legal guardian on behalf of a child who is not capable should be in the child's best interests, preserve the child's dignity, and follow all reasonable wishes of the child.
- A child in care has the right to any health care option available to a child not in care.
- Planning for a child's health care should be done locally wherever possible and, subject to the privacy rights of the child, may include the child, the child's family, social workers, physicians, health care providers, foster parents, aboriginal community representatives and other significant people involved in the child's life.
- Critical health care decisions are made after consultation between the guardianship worker and his or her supervisor or manager. Decisions themselves are the responsibility of the supervisor/manager. (Note, however, that the decision to consent to a DNR Order is made by the Director.) If you are uncertain about who has the right to consent to a health care decision, see the table on page 9. Disagreements over a critical health care decision may be referred to an ethics committee (see page 15).

Terms used in these practice guidelines

advance health care directive	<p>A declaration made by a capable child or the legal guardian of an incapable child that states the known wishes, values, and beliefs of the child regarding consent to health care measures to be taken in the event of incapability, emergency, or imminent death. Subject to s. 29 of the CFCSA, a capable child may also indicate what health care measures she or he does not want.</p> <p>The physician's signature on the advance health care directive indicates that the physician is aware of the contents of the declaration.</p>
capability	<p>A child's demonstrated understanding of the nature of the proposed health care, the available options, the reason for the health care being offered and the consequences, risks and benefits of the proposed health care. In this document, the terms <i>capability</i> and <i>capable</i> are used in place of the terms <i>capacity</i> and <i>with capacity</i> to indicate a child's level of understanding.</p>
Do Not Resuscitate Order	<p>A medical order completed and signed by two physicians directing health professionals (nurses, ambulance attendants, etc.) not to engage in resuscitation efforts in the event of cardiac or respiratory arrest. The DNR Order is also signed by a witness. The term <i>do not resuscitate</i> is understood not to include clearing the upper airway in the event of obstruction (i.e., choking on food), which will be attempted regardless of a DNR Order.</p>
Ethics Committee	<p>A committee established by a local health authority for the purpose of reviewing ethical issues pertaining to health care. An ethics committee usually comprises: pastoral representation, physicians (including specialists), health authorities, psychologists /social workers, legal representation, an ethicist and a member from the community.</p>
health care	<p>Anything that is done for a therapeutic, preventive, palliative, cosmetic or other purpose related to maintaining health.</p>
parent	<p>The mother of a child, the father of a child, a person to whom custody of a child has been granted by a court of competent jurisdiction or by an agreement, or a person with whom a child resides and who stands in place of the child's mother or father.</p>
legal guardian	<p>The person who holds parental rights with respect to a child. The legal guardian may be the child's parent or a person who has guardianship by operation of a statute (<i>Family Relations Act</i>, <i>Divorce Act</i>, <i>CFCSA</i>), as a result of a court order, by operation of a will, or pursuant to a written agreement. Legal guardianship can be jointly held, usually by two parents. In the case of joint guardianship, both guardians must agree to significant decisions regarding the child.</p>
other significant people	<p>People who are identified by the child or the child's parent as providing meaningful support, whether or not they are related to the child biologically or through marriage.</p>

I. Your role in managing critical health care decisions

Generally, your role in managing critical health care decisions is to:

- ensure the child's safety and well-being
- make all reasonable efforts to ensure that a capable child's decision is informed and is made voluntarily and free of coercion from others
- coordinate discussion among those involved in planning for the child's care, including the child wherever possible
- ensure that the child's wishes, if known and in the child's best interests, are followed (see Appendix 3), and if the child's wishes are not known, to enter into discussion with those involved in planning for the child's care to determine what wishes, beliefs or values of the child's should be taken into account
- where necessary, facilitate referral of the case to an ethics committee
- ensure that all applicable practice standards are met

Beyond these general responsibilities, your specific role will be determined by:

- the child's legal status in relation to the Ministry
- the child's capability to consent to health care

Managing critical health decisions about a child in care

If you are managing a critical health decision about a child in care, your role is to carry out your guardianship duties and responsibilities as defined by the ministry's Practice Standards for Guardianship, specifically by Practice Standard #32 (see Appendix 2).

The following summarizes the main practice guidelines that apply as part of your guardianship roles and responsibilities:

- Subject to s. 29, a capable child in care has the right to consent to a health care decision.
- If a child in care has been assessed as incapable, the child's legal status with the ministry will determine who may consent to the decision (see page 9). Note that this decision is subject to s. 29.
- If there are doubts about the child's capability to consent, you must arrange for the child to have a formal capability assessment (see page 10).
- When a critical health care decision about a child in care is required, consult with and receive the approval of your supervisor and either the regional child protection manager or community service manager.
- In the case of an incapable child in continuing care, your guardianship role includes the authority to consent to health care, to decide who should be included in any health care planning, to authorize an advance health care directive (except a Do Not Resuscitate Order; see below) and to make any other decision that is in the child's best interest.
- Notify the Director's office any time there is a question of whether to withdraw life supports from a child in care. A decision to withdraw life supports requires the Director's consent.

*Supervisors,
Protection Managers
& Community Service
Managers*

Managing critical health decisions in a child protection case

Where a child protection intake involves a critical health care decision, your role is primarily to ensure the child's safety and well-being as set out in the *Practice Standards for Child Protection*. If the child is already receiving protection services, your role is to ensure that the child receives necessary health care.

In addition to the general responsibilities shown on page 6, the following summarizes the main practice principles that apply in a child protection case:

- A capable child has the right to consent to a critical health care decision.
- If the child lacks capability, the child's legal guardian has the right to consent.
- If there is any question about the child's capability, you may consider a formal assessment (see page 10).
- If the child's physician believes that either the capable child or the legal guardian of an incapable child is making a health care decision that will not preserve the child's life or prevent serious or permanent impairment of the child's life, the physician may make a protection report.
- Where a capable child or the legal guardian of an incapable child refuses to consent to health care that a physician believes is necessary to preserve the child's life or prevent serious or permanent impairment of the child's life, your Immediate Safety Plan and/or Risk Reduction Service Plan for the child may include removing the child or applying for a s. 29 order authorizing the health care, and, where necessary, completing an advance health care directive.
- In carrying out a child protection investigation, Practice Standard #14 requires that you see and interview the child, all other children in the household, and the parents/caregivers.
- If a critical health care decision is required, consult with and receive the approval of your supervisor and regional child protection manager.

Supervisors and
Protection Managers

Deciding who to involve in making critical health care decisions

The legal status of the child will determine who is involved in making a critical health care decision. While each situation will be different, the following people are usually involved to support a capable child or the legal guardian of an incapable child to make informed and medically appropriate health care decisions:

- the child
- the child's family
- health care providers (including the primary care physician)
- representatives from the child's aboriginal community where appropriate
- foster parent(s) or other caregivers
- social workers
- other significant people identified by the child and family

Deciding who to involve in a critical health care decision requires careful balancing of the child's right to confidentiality and your need to disclose information to ensure the child's safety and well-being (see s. 79 of the *CFCSA*).

Where a medically fragile child is the subject of a child protection investigation, your Immediate Safety Plan and Risk Reduction Service Plan should address the decision of whom to involve in making critical health care decisions.

➤ **Guardianship responsibilities**

Where a child is in continuing care, you may decide to include the parents and family of the child in the planning after considering the best interests of the child. Where appropriate, you may also include:

- health care providers (including the primary care physician)
- representatives from the child's aboriginal community where appropriate
- foster parent(s) or other caregivers
- social workers
- other significant people identified by the child and family

Note that the Public Trustee of British Columbia is guardian of the child's estate and should be notified of any critical health care decision.

Who may consent to or refuse health care decisions including Advance Health Care Directives and Do Not Resuscitate Orders

	Who makes the decision	Notes
Child in care		
With capability	The child	The child's right to consent to or refuse health care under section 17 of the <i>Infants Act</i> is qualified by s. 29 of the <i>CFCSA</i> (see Appendix 1).
Without capability		
a) In care under a continuing custody order	Director's delegate	<p>Subject to the child's privacy rights, all parties who have significant involvement with the child should meet to discuss the proposed health care. Your decision is reached following this meeting and consultation with your supervisor, RCPM, and CSM.</p> <p>If the parents of a child are involved and disagree with the proposed health care, they may make an application to the BC Supreme Court under its <i>parents patriae</i> jurisdiction.</p>
b) In care by agreement	Child's parent, unless otherwise stated in the agreement	<p>Wherever possible, support should be provided to the parent in making critical health care decisions. Consider having all involved parties meet to discuss the child's circumstances and the proposed health care options.</p> <p>Note that the parent has the right to terminate an agreement at any time.</p>
c) In care by means of a removal and prior to an order being made	Child's parent (see s. 32)	You may consent to necessary health care for the child if a health care provider indicates that health care should be provided without delay. In this case, you must make every effort to notify the parent (see s. 32)
d) In care by means of an interim custody order or temporary custody order	Director's delegate	Where appropriate every reasonable effort should be made to consult with the child's parent before making any significant decision about the child's health care. (If you have any questions about your obligation to contact the parent, consult with contract legal counsel.)
Child not in care		
With capability	The child	The child's right to consent to or refuse health care under section 17 of the <i>Infants Act</i> is qualified by s. 29 of the <i>CF&CS Act</i> (see Appendix 1).
Without capability	Child's parent	If the child is the subject of a protection report, the report must be assessed and, if necessary, investigated. See <i>Practice Standards for Child Protection</i> .

You must notify the Director's Office before making any decision to withdraw life supports or end intensive life support treatment to continue a child's life.

2. Determining a child's capability

For more
information
see Appendix 5

Where a child's capability to consent to health care is in question, arrange a formal assessment to determine whether the child understands the nature, consequences and reasonably foreseeable benefits and risks of the proposed health care.

Where a team of professionals is involved with the child, the decision to proceed with a capability assessment should be discussed with the team.

➤ **Guardianship responsibility**

Where there is doubt about the capability of a child in care to consent to health care, ensure that the child has access to a formal capability assessment and arrange the assessment with two physicians, one of whom should be the child's primary physician.

Who does the formal assessment of capability?

The assessment should be completed by two physicians, independent of one another, one of whom should be the physician who knows the child best (usually the child's primary physician).

Wherever possible, the physicians, psychiatrists or qualified psychologists making the assessment should:

- know the child
- assess the child's maturity
- determine the influence of religious and cultural factors in the child's capability to consent
- ensure the assessment is voluntary and free of coercion
- when feasible, make repeated observations and have ample time for reflection and consideration of the child's capability

In emergency situations only, the capability assessment may be completed by two physicians who are unknown to the child.

Where the assessing physicians disagree or have difficulty reaching a decision, discuss the results with your supervisor and, if necessary, request a more comprehensive assessment by a psychiatrist or psychologist.

Inform each physician that you require a written report of the assessment results.

See Appendix 5 for guidelines to provide to physicians who are assessing the child's capability to consent.

If the child refuses to cooperate with having a capability assessment completed

If there are questions about a child's capability to consent and the child refuses to undergo a capability assessment, consult with the parties involved in planning for the child's health care and propose a referral to an ethics committee for review and recommendation (see page 15).

➤ **Guardianship responsibility**

In the case of a child in continuing care who refuses to have a capability assessment completed, refer the matter to an ethics committee (see page 15).

3. Preparing an advance health care directive

An advance health care directive states what actions the capable child or the incapable child's legal guardian wants in the event of an emergency, imminent death, or incapability of the child. The advance directive allows decisions to be made in advance of the time when they must be made. An advance health care directive should be as explicit as possible.

Although it is strongly recommended that advance health care directives be completed for children who are medically fragile, they are not mandatory. A capable child or the legal guardian of an incapable child may refuse to complete an advance directive. This decision should be respected.

In general, your role in planning and preparing an advance health care directive is to:

- help the child and family understand and adjust to the idea of an advance directive – you may have to bring up the topic several times before they are emotionally ready to deal with such difficult decisions
- facilitate a structured discussion about the directive with the child (where appropriate), the child's parent, and the health care provider
- assist the child or the parent to complete the advance health care directive in collaboration with the health care providers and others
- coordinate efforts with health care providers to ensure the child and the parent receive the information they need to fully understand the child's medical condition, applicable treatment options, and the purpose of the advance health care directive
- ensure the child and family know they can obtain a second or third opinion before completing an advance directive
- ensure that such information is introduced in a timely and sensitive manner
- assist in reviewing and updating the advance directive as needed
- make all reasonable efforts to ensure that any decisions in the advance directive are followed
- ensure that health care planning is sensitive toward the child's culture, race and religious heritage

► **Guardianship responsibilities**

The child's legal status will determine which items from the above list are appropriate in the circumstances.

In the case of a child in continuing care, the child's capability will determine who makes the decision whether to complete an advance health care directive. (For other children in care, see page 9.)

- If the child is assessed as capable, discuss the advance health care directive with the child. The final decision is made by the child. (Note, however, that you may consider an application for a court order authorizing health care under s. 29 – see Appendix 1).
- If the child is assessed as incapable, you are expected to complete an advance health care directive. Consult with the physician and other individuals involved with the child, request other medical opinions, and discuss the case with your supervisor and program managers before preparing an advance directive.

Completing an advance health care directive

An advance health care directive may be part of a comprehensive health care plan for a child. An advance directive usually includes:

- identifying information about the child
- the physician's order concerning resuscitation of the child, where appropriate (see Do Not Resuscitate Orders, below)
- the degree of intervention which will be provided to the child
- other specific health care instructions
- authorization by the capable child or the legal guardian of an incapable child
- a regular review schedule

➤ Reviewing an advance directive

Besides regular scheduled reviews, advance directives should be reviewed and rewritten, if necessary, whenever there is a change in the child's medical condition or capability to consent (for example, if the child's medical condition improves or worsens).

➤ Revoking or changing an advance directive

A capable child or the legal guardian of an incapable child may change or revoke an advance directive at any time.

If the child's legal guardian wishes to change or revoke an advance directive made by a capable child at a time when the child has become incapable, refer the issue to an ethics committee for review and recommendation (see page 15).

Do not resuscitate orders

Where a child has a terminal illness or is in a state of permanent unconsciousness, an advance health care directive may include a Do Not Resuscitate (DNR) Order.

See page 9 to determine whose consent is required for a DNR Order.

➤ Guardianship responsibilities

Your role when a DNR Order is being contemplated for a child in care includes:

- consulting with the child's physician (even when a DNR Order is only being considered by a health care provider or parent)
- obtaining a second medical opinion about the child's prognosis
- obtaining a written report on the child's prognosis from each physician consulted
- where the child is hospitalized, contacting the hospital social worker to ensure efficient communication with the child's physician as well as with the rest of the health care team involved with the child
- early involvement in the decision making process to ensure guardianship responsibilities and obligations are met
- ensuring that the child and family (if involved) have full understanding of the child's medical condition and the consequences of a DNR order

- where appropriate, day-to-day involvement with the child, family and health care providers to monitor the child's health situation and to have a clear understanding of the dynamics and complexities involved
- meeting with the child's physician, asking questions and providing feedback about decisions related to the child's health care
- providing the Director's Office with the information needed for the Director to make the decision whether to consent to the DNR
- referring the matter to an ethics committee, if necessary

4. Resolving disagreements over a health care decision

If a capable child or the legal guardian of an incapable child refuses to consent to health care that a physician believes is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's life, your role is to facilitate a discussion between all parties involved in decisions about the child's care in order to reach a resolution of the issues. The parties may include:

- the child
- members of the child's immediate and extended family
- other social workers involved with the child
- foster parents
- health care providers, including physicians, nurses, specialists or others
- if the child is aboriginal, representatives of the child's aboriginal community
- any other significant people identified by the child.

Depending on the urgency of the child's need for health care, your discussion with the parties involved may lead to one or more of the following actions:

- a request that the physician talk to the child (or the legal guardian of an incapable child) in order to help the child or legal guardian understand the nature of the proposed health care and why it is being proposed
- a decision to honour the child's wishes
- a decision to apply for a section 29 order authorizing necessary health care – (see Appendix 4: A Child's Right to Determine Health Care)
- referral of the matter to an ethics committee for review and recommendation
- removal of the child if necessary to ensure the child receives the necessary health care

If a child (capable or incapable) refuses to have the health care decision reviewed by an ethics committee

Consult with your regional child protection manager/community service manager for the purpose of preparing a presentation to an ethics committee. In this instance the referral to an ethics committee is made to address the safety and well-being of the child and is made independent of the child's agreement.

► Guardianship responsibility

Where a capable child in care or the legal guardian of an incapable child in care refuses to consent to health care that a physician believes is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's life, you may apply for a s. 29 order authorizing the health care.

In the case of incapable child in continuing care, your guardianship responsibilities include consenting to health care. Before making a decision, consult with your supervisor and regional program manager about the child's medical condition, the prognosis, and the health care options and consequences of each option.

5. Referring disputed health care matters to an ethics committee

Ethics committees are established by local health authorities or hospitals for the purpose of reviewing ethical issues pertaining to health care. Where a child or the legal guardian of a child disagrees with a health care decision being proposed, whether as the result of a child protection report or a guardianship decision, the case may be referred to an ethics committee for their recommendations.

When to refer a case to an ethics committee

You may decide to ask an ethics committee to review and make recommendations in cases such as the following:

- See page 10 • If there are questions about a child's capability to consent and the child refuses to undergo a capability assessment
- See page 14 • If a child assessed as capable refuses to consent to health care that a physician believes is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's life
- See page 14 • If the legal guardian of an incapable child refuses to consent to health care that a physician indicates is in the child's best interest
- See page 14 • If a child refuses to have a health care decision reviewed by an ethics committee

If you believe a case should be reviewed by an ethics committee, consult with your regional child protection manager or community service manager. These managers in each region have received special training in preparing presentations for an ethics committee and will be able to help you collect necessary information, identify individuals who need to be involved, and co-ordinate and deliver the presentation to the ethics committee.

➤ If an ethics committee recommends the health care as being in the child's best interest and the capable child continues to refuse consent

Before applying to the court for a s. 29 order to authorize necessary health care:

- Supervisor Action
- discuss the matter with your supervisor and then consult with legal counsel
 - consult with the child's physician to be certain that the physician is committed to carrying out the health care service once the court authorizes such health care.

Note that a s. 29 order does not require a physician to carry out the health care, but rather, authorizes the health care to be carried out over and above the wishes of the child or legal guardian.

➤ If an ethics committee recommends the health care and the legal guardian continues to disagree with the proposed health care.

- Supervisor Action
- Consult with the child and your supervisor, and then with legal counsel in order to decide which of the following actions to take:

- in situations that are not urgent, to apply for a s. 29 order authorizing necessary health care
- in urgent situations, to remove the child under s. 30 and authorize health care as described under s. 32
- if the child is already in care, to authorize necessary health care under s. 32. Note that s. 32 does not provide authority to override a decision of a capable child.

Referrals to the BC Children's Hospital Ethics Committee

The Ethics Committee of BC Children's Hospital is available to provide consultation to the Ministry on matters that are clinically or ethically problematic relating to medically fragile children.

The BC Children's Hospital Ethics Committee is available to the ministry anywhere in the province where no appropriate local ethics committee is available.

Note that the Ethics Committee provides objective advice and recommendations to assist in care, but is not intended to assume any decision-making role in the actual provision of health care.

If you are considering an application to the Ethics Committee, the case should meet the following criteria:

- Referrals to the Ethics Committee are limited to complex and difficult cases.
- Referrals must have been subject to full and thorough discussion in advance with the child, family members and members of the health team as available and appropriate.
- Discussions must have identified specific questions or particular issues for the Ethics Committee's recommendations or other assistance.

Making a referral

- The initial referral is made by telephone by the regional child protection manager/community service manager or their delegate to the Ethics Committee Chair or delegate. (Contact (604) 875-2161. The paging service will contact the person who is on call for the Ethics Committee.)
- Following the initial telephone referral, arrangements are to be made to fax written documentation to the Chair or delegate.
- The Ethics Committee usually can arrange meetings on very short notice (48-72 hours), if the case is urgent. In non-urgent cases, meetings will be arranged according to the availability of committee members and the time required to gather information about the case.
- Once the Ethics Committee has met, verbal recommendations are available within 24 hours; the written version may take additional time to prepare.

Preparing a case for presentation to the Ethics Committee

- Consult with the health care providers involved with the child and with your regional child protection manager/community service manager in order to gather all the details about the case.
- Notify all members of the child's health care team that the case is to be presented to the Ethics Committee. Permission from these individuals is not required to present a case to the Ethics Committee.
- Participate with the physician and other health care providers involved with the child in developing a summary to be forwarded to the Ethics Committee. The summary should include:
 - the child's identification
 - pertinent medical facts

- the child's and/or parent's health care preferences
- the views of family, aboriginal community, and other individuals involved with the child
- the views of caregivers
- legal, administrative and external factors
- a clear statement of the question or problem and a request for assistance by the Ethics Committee

The child's physician is usually in the best position to take the lead in presenting the case to the Ethics Committee. In addition to being involved with the physician in preparing the information being submitted to the Ethics Committee, you are expected to participate in the presentation where appropriate.

Appendix I: Section 29, Child, Family and Community Service Act

- (1) If a child or a parent of a child refuses to give consent to health care that, in the opinion of two medical practitioners, is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's health, a director may apply to the court for an order under this section.
- (2) At least two days before the date set for hearing the application, notice of the time, date and place of the hearing must be served on
 - (a) each parent,
 - (b) the child, if capable of consenting to health care, and
 - (c) any other person the court directs.
- (3) If satisfied that the health care is necessary to preserve the child's life or to prevent serious or permanent impairment of the child's health, the court may make an order
 - (a) authorizing the health care,
 - (b) prohibiting any person from obstructing the provision of the health care,
 - (c) requiring a parent or another person to deliver the child to the place where the health care will be provided, and
 - (d) including any other terms, including the duration of the order, that the court considers necessary.
- (4) In this section, "child" includes a child in care.
- (5) This section does not limit the director's power to remove the child under section 30 or to take any other steps authorized by this Act to protect the child.

Appendix 2: Guardianship Practice Standard #32

Managing Critical Health Care Decisions Including Advance Health Care Directives for the Child in Care

In carrying out your guardianship duties and responsibilities in relation to a child in care who is terminally ill or who suffers from a potentially life-threatening medical condition, you must give paramount consideration to the safety and well-being of the child, and:

- ensure that the situation is reported to the director (Practice Standard 13)
- ensure that you, the child and the child's parent(s) and/or caregiver are fully informed about the child's medical condition, the nature of any proposed health care and the consequences, risks and benefits associated with the proposed health care
- determine the scope of your role and authority in making health care decisions for the child
- ensure that, when there are doubts about the child's capability to consent, the child has access to a formal capability assessment
- facilitate a structured discussion with the child and/or the child's parent(s) about advance health care directives, when appropriate, and
- ensure that a documented health care plan is developed for the child and that it includes a determination of the child's capability to consent to his or her own health care, your role as well as the role of the child's parent(s) in making health care decisions on behalf of the child, and any critical health care decisions, including any advance health care directives agreed upon with the child and/or the child's parent(s).

In situations involving placement of hospitalized high-risk or medically fragile infants or children, you must ensure that:

- there is a discharge planning meeting before the child leaves the hospital that includes a plan for ongoing medical care, as well as training, support and supervision of the caregiver in providing for the child's daily needs
- you and the child's caregiver, as well as the child's parent(s), are in attendance at the discharge planning meeting
- the caregiver has received appropriate and adequate training to care for the child and to monitor the child's health care needs, and
- the child's health care plan is reviewed at least every six months.

Appendix 3: Sample Advance Health Care Directive

ADVANCE HEALTH CARE DIRECTIVE FOR CHILDREN		
CHILD'S SURNAME	GIVEN NAME(S)	BIRTHDATE (dd/mm/yy)
ADDRESS (home/foster family/facility)	PHONE	
PHYSICIAN'S NAME	PHONE	FAX
BC PERSONAL HEALTH #	ABORIGINAL COMMUNITY CONTACT (see CFCs Regulation: Schedules 1 & 2)	
LEGAL GUARDIAN	LEGAL STATUS	
ADDRESS	PHONE	
MINISTRY FOR CHILDREN AND FAMILIES SOCIAL WORKER:		
ADDRESS	PHONE	
<p>A. CARDIOPULMONARY RESUSCITATION - The instruction below applies only should the child have or develop a terminal illness or be in a state of permanent unconsciousness.</p> <p>In the event of witnessed cardiac and/or respiratory stress (indicate one only):</p> <p><input type="checkbox"/> Do not resuscitate (No cardiac compressions, endotracheal intubation, advanced airways management, defibrillation, intravenous resuscitation medications or CPR).</p> <p><input type="checkbox"/> Initiate basic and advanced cardiopulmonary resuscitation.</p> <p><input type="checkbox"/> No decision about resuscitation is made at this time.</p>		
<p>A.2 PHYSICIAN'S ORDER - Complete only if no cardiopulmonary resuscitation is to be provided</p> <p>The subject child of this advance health care directive has been diagnosed as having a terminal illness or is considered to be near the end of her/his life. I have discussed the prognosis of this illness, the child's life expectancy, the child's wishes (where possible), and the health care options with the child or the child's parent (if the child has been assessed as incapable). Based on this, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect unless rescinded and should be reviewed in 6 months time.</p>		
SIGNATURE OF CHILD, PARENT, OR DIRECTOR	ATTENDING PHYSICIAN'S SIGNATURE	
EXPIRY DATE	ATTENDING PHYSICIAN'S ADDRESS & PHONE NUMBER	
<p>NOTE: A physician's "NO CPR" order is necessary for ambulance personnel and health care providers in institutional settings to be able to respect the child's or legal guardian's "NO CPR" instructions.</p>		

B. LEVELS OF INTERVENTION - In the event of an irreversible life threatening illness leading to imminent death, or of natural end of life, direction is given to provide the following (indicate one):

- ☐ **LEVEL ONE DO NOT TRANSFER TO HOSPITAL** Supportive care only (i.e., nursing care, pain and other symptom relief, oral nutrition and hydration, psychological and spiritual support)
- ☐ **LEVEL TWO DO NOT TRANSFER TO HOSPITAL** Therapeutic measures and supportive care without transfer to an acute care hospital (includes supportive care as outlined in Level One and medications such as diuretics or antibiotics if indicated). No transfer to an acute care hospital unless adequate comfort measures cannot be provided.
- ☐ **LEVEL THREE TRANSFER TO AN ACUTE CARE HOSPITAL** if necessary but excluding admission to an intensive care unit.
- ☐ **LEVEL FOUR TRANSFER TO AN ACUTE CARE HOSPITAL** with maximum therapeutic effort and if necessary admission to the intensive care unit.
- ☐ **NO DECISION ABOUT DEGREE OF INTERVENTION IS MADE AT THIS TIME**

C. (Optional) OTHER SPECIFIC HEALTH CARE INSTRUCTIONS (for example, use of medications, technology, pastoral care, natural end of life to take place at home)

- ☐ A plan exists for the child's health care based upon integrated case management and service delivery (attach a copy to this advance health care directive).

D. AUTHORIZATION BY CAPABLE CHILD OR LEGAL GUARDIAN

1. I have read and understood all sections of this advance health care directive (sections A-D).
2. I hereby revoke all previous advance directives. This directive is to be followed by all health care providers (and where applicable, Ministry for Children and Families' employees and any other significant individuals involved in the child's life).

Signature of child, parent, or director

Date

First witness (print name)

Signature

Date

Physician (print name)

Physician's Signature

Date

Physician's signature does not signify either acceptance or approval of the advance health care directive; the physician's signature is an indication that she/he has read the declaration and is aware of its contents.

E. REVIEW (If revised, complete another form and destroy this form)

The signature of the capable child or of the parent or director where the child has been assessed as incapable below indicates that no changes were made to the advance directive on the date of the review:

Signature of child, parent, or director

Date

Signature

Date

Signature

Date

Appendix 4: A child's right to determine health care

Introduction

An individual's right to be free from non-consensual medical treatment is a concept deeply rooted in our case law. Every person's body is considered inviolate and, accordingly, every competent person has the right to be free from unwanted medical treatment.

Under the common law, the right of a parent to control his or her minor child declines with the child's advancing age. In many jurisdictions, in the absence of specific legislation, the capacity of a given child to consent to or refuse medical treatment is determined by the child's age, intelligence and maturity. In one British case, the court held that once a child has sufficient understanding and intelligence, the parental right yields to the child's right to consent to or refuse treatment. In another British case, the court held that in some stage in the child's development, the parents and the child have a concurrent right to consent to or refuse the treatment. The balance of this authority shifts towards the child as the child matures.

For a child to be deemed competent to decide medical treatment, he or she must have a full understanding and appreciation of the treatment, potential risks and side effects, and the anticipated consequences of a failure to treat.

With a child, therefore, there is no presumption that he or she is competent, regardless of age.

While the courts can authorize medical intervention, no court has the authority to compel or order a medical practitioner to perform a medical procedure.

Section 17 of the *Infants Act*

In 1993, s. 17 of the *Infants Act* was proclaimed in force. (Note that prior to the renumbering of various Acts in 1996, the present s. 17 of the *Infants Act* was s. 16.)

This section permits a child, whom a health care provider has determined understands the nature and consequences and reasonably foreseeable benefits and risks of the health care, to consent to it, independently of his or her parents or guardians. Additionally, the health care provider must determine that the proposed course of health care is in the child's best interests. In order to give meaning to the section, it is necessary to read in *or refuse* wherever the word *consent* is used in the section.

This section does no more than incorporate the common law into statute and provides some certainty with regard to those to whom it applies. Note that the child's capacity is not directly determined by the child reaching a specified age.

The Child, Family & Community Service Act, Section 29

Section 29 of the CFCSA qualifies the rights a child enjoys under s. 17 of the *Infants Act*. Section 29 operates in circumstances where a mature minor, capable of consenting, refuses to give consent to health care that, in the opinion of two medical practitioners, is necessary to preserve the child's life or to prevent serious or permanent impairment of the mature minor's health.

Under this section, a child is not removed by the Director, but the court can, nevertheless, make an order authorizing the required health care. It must be emphasized that although a court can authorize health care, no court has the

authority to compel or order a medical practitioner or other health care provider to perform a medical procedure.

Given this limitation, prior to making an application to court under s. 29, you should determine in advance that the health care provider will perform the required medical procedure if authorized to do so by the court but faced with a continued refusal from the mature minor. At least one hospital in the Lower Mainland will not perform a medical procedure without the express consent of the child, regardless of whether a court order authorizes the treatment.

Sections 30 and 31

Section 30 of the CFCSA enables the Director to remove a child if the child's health or safety is in immediate danger.

Section 31 requires the Director to make all reasonable efforts to notify each parent of a child after the child has been removed.

Following a removal under s. 30, the Director has the care of the child. Care is defined to mean "physical care and control of the child." While the child is in the Director's care, s. 32(2) of the CFCSA permits the Director to authorize health care providers to examine the child and to consent to necessary health care for the child if, in the opinion of the health care provider, the health care should be provided without delay.

It should be noted that s. 32(4) specifically limits the Director's authority in that it states that s. 32(2) does not affect the child's rights under s. 17 of the *Infants Act* to consent to or refuse health care. Therefore, when faced with a child refusing what is deemed to be necessary health care, s. 32 is not authority for the Director to override the views of a mature minor. Section 32 applies only in situations where a child is deemed not to have capacity to consent to or refuse health care.

Summary

Section 17 of the *Infants Act* permits a minor who, in the opinion of the health care provider, understands the nature and consequences of and reasonably foreseeable benefits and risks of the treatment to consent to or refuse the proposed treatment, independently of his or her parents or guardians. The health care provider must also conclude that the health care is in the child's best interest.

If a Director were to remove such a child, the Director merely steps into the shoes of the parent and has no more authority to override the decision of the child than does the child's parents.

Section 29 of the CFCSA was enacted to address situations where it has been determined that the minor has capacity under the *Infants Act*, but is, nevertheless, refusing treatment deemed necessary to preserve his or her life or to prevent permanent serious impairment of his or her health.

Appendix 5: Determining the capability of a child – Guidelines for physicians

The following are suggested guidelines for physicians (or other health care providers) for determining a child's capability to make critical health care decisions.

Section 17 of the *Infants Act* permits a mature minor, who in the opinion of a health care provider understands the nature and consequences and reasonably foreseeable benefits and risks of health care, to consent to it, independently of her or his parents or guardians. Additionally, the health care provider must determine that the proposed health care is in the child's best interests. In order to give meaning to the section, it is necessary to read in or refuse wherever the word *consent* is used in the section.

Section 29 of the *Child, Family and Community Service Act* operates in circumstances where a mature minor, found to have capacity under section 17 of the *Infants Act*, refuses to consent to proposed health care, that, in the opinion of two medical practitioners, is necessary to preserve the mature minor's life or prevent serious or permanent impairment to her or his health.

While the *Infants Act* enables "any health care provider" to determine the capability of the child to consent, it is recommended that two physicians make this determination in case of the need to use the provisions of the *Act* in the future.

It is recommended that the following be included in a determination of capability of a child to consent. Capability is the determination that the child understands the nature and consequences and reasonably foreseeable benefits and risks of health care:

- The child is able to repeat and explain the procedure or plan of care in his/her own words or manner;
- The child is able to provide clear, unambiguous answers to questions;
- The child provides consistent answers and information;
- The child asks pertinent questions to indicate their understanding; and,
- The child demonstrates an understanding of the consequences of consenting to health care.

It is preferable that the physicians or health care provider making the assessment:

- know the child;
- make an assessment of the child's maturity;
- have taken into consideration any cultural factors that might affect the child's capability to consent and the child's manner of communication (appropriate to the child's skills and abilities);
- has taken steps to ensure that the assessment is voluntary and free of coercion; and,
- when feasible, makes repeated observations and has ample time for reflection and consideration.

Where there is disagreement or different judgments from two or more physicians, a more comprehensive assessment by a psychiatrist or psychologist maybe considered.